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Measuring the subjective well-being of people with profound intellectual and multiple disabilities

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Background

- Challenge of evaluating QOL in persons with profound intellectual and multiple disabilities (PIMD)
- Especially the component of subjective well-being (SWB) is difficult to evaluate in persons with PIMD
 - self-reports are not applicable
 - proxy-approach ⇒ critical comments



Aim

Investigate the subjective well-being of people with PIMD by focusing on the experience of positive or negative emotions or mood ('hedonic level' of SWB):

1. Gathering information about SWB using the MIPQ
2. Development of non-interpretative measure of SWB



Study 1: Aim

(Vos, De Cock, Petry, Van den Noortgate & Maes, 2010a)

Investigation of the SWB of people with PIMD using the MIPQ (Ross & Oliver, 2003):

- a) Do people with PIMD have the same SWB as people with severe or no intellectual disabilities?
- b) Which factors contribute to the SWB of people with severe or profound intellectual disabilities?
- c) Do the same factors contribute to objective and subjective QOL?

Study 1: methods

- 354 informants completed the MIPQ about 360 persons with severe or profound ID
- The informants completed a questionnaire about the person, setting and informant characteristics.



Study 1: Results

1. People with profound ID scored lower than people with severe ID
2. Mean of people with profound ID significant $<$ 70% of scale maximum; people with severe significant $>$ 70% of scale maximum



Study 1: Results

3. Higher age, medical problems (constipation), medical treatment (sedatives), higher support needs, having additional sensorial disabilities, having psychiatric problems (autism), seeing a psychiatrist and having feeding problems have a negative effect on the total MIPQ score
4. Only medical problems associated with both objective and subjective QOL

Study 1: Conclusion

1. People with profound ID are at greater risk of having low subjective well-being
2. Different characteristics are associated with subjective and objective QOL → important to measure both
3. Need to include more relevant service and staff characteristics
4. Need for a measurement of subjective well-being that does not rely on proxies

Study 2: Aim

(Vos, De Cock, Petry, Van den Noortgate & Maes, 2010b)

Finding physiological parameters that can distinguish between positive and negative emotions in people with PIMD



Study 2: Participants

- Three persons with PIMD (two men and one women)
- All had epilepsy which was under control through medication



Study 2: Independent variables

- 4 real life situations:
 - Group activity
 - Individual activity with member of support staff
 - A situation where the participant was alone
 - A meal
- Direct support staff selected
 - a positive stimulus for each situation
 - a negative stimulus for the individual activity and meal or group situation
- 6 stimuli situations for each participant (4 positive; 2 negative). Each of the situations was videotaped

Study 2: Measures

- Direct behavioural measure:
 - Developed by Petry & Maes (2006)
 - Ask support staff to identify behaviours most used to express positive and negative emotion (affective profile)
 - Videotape the stimuli situations
 - Code each behaviour of the participant as:
 - ‘expressing a very negative emotion’ (code 1)
 - ‘expressing a negative emotion’ (code 2)
 - ‘expressing neither a negative, neither a positive emotion’ (code 3)
 - ‘expressing a positive emotion’ (code 4)
 - ‘expressing a very positive emotion’ (code 5)
- LifeShirt technology (VivoMetrics, Inc., Ventura, CA) to measure respirational, cardiovascular and electro dermal parameters

Study 2: Research questions

1. Are there differences in the physiological parameters between the positive and negative stimuli situations?
2. Are behavioural codes indicating positive and negative emotions correlated with the physiological parameters?



Study 2: Results

1. Differences between positive and negative situations:
 1. Included only positive and negative individual activity with member of the direct support staff
 2. Respiration:
 - We found differences between positive and negative stimuli situations in 9 parameters (for full results see article)
 3. Electro dermal responses:
 - Higher skin conductance level in the positive staff situation then in the negative staff situation



Study 2: Results

1. Differences between positive and negative situations:
 4. Cardiovascular responses:
 - No differences in heart rate
 - Higher Heart Rate Variability (HRV) in negative staff stimuli situations



Study 2: Results

2. Relations with behavioural codes:

– Respiration:

- 12 parameters related to the valence of the expressed emotions
- 6 parameters related to the intensity of the expressed emotion

– Electro dermal response:

- There was a positive relationship between the positivity of the expressed emotion and the skin conductance

– Heart rate:

- There was no relationship between heart rate and the valence of the expressed emotion
- Heart rate had a positive relationship with the intensity of the expressed emotion



Study 2: Conclusion

- Alternative interpretation to results:
 - Positive situations elicit emotions higher on arousal dimension than the negative situations
 - The difference in arousal dimension is the cause of the results, not the valence of the emotions
- Alternative interpretation not necessarily a problem:
 - In negative situations people will perform fight or flight behaviours
 - People with PIMD can't fight the negative stimuli and can't flee from them
 - Possible they regulate their attention away from the negative stimuli
 - this interpretation is supported by the higher heart rate variability in the negative condition

Study 2: Conclusion

- Positive emotions:
 - fast and shallow breathing pattern – maybe due to silent laughter- a high mean inspiratory flow and less thoracic breathing.
 - high skin conductance → more sympathetic activation – maybe due to the fact that positive situations elicit more arousal.
- Negative emotions:
 - slow and shallow breathing pattern – maybe due to attentional shift.
 - Low skin conductance
 - Higher Heart Rate Variability → more parasympathic activation– maybe due to attentional regulation

Study 3: current research

- Aim:
 - Trying to replicating study 2 with 28 participants
 - Investigating role of alertness in physiology
 - Investigating relationship mood and physiology
- Measures:
 - Presentation of 4 positive and 4 negative stimuli in a one on one situation
 - MIPQ
 - Direct behavioural measure
 - Alertness profile
 - Dreamer (Medatec) to measure physiological parameters

General conclusion

- Important to investigate subjective well-being in people with PIMD
- Need for research to find service and staff characteristics contributing to subjective well-being
- Need for a non-interpretative measure
- Physiological measurement seems promising but still more research needed

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